

Future Directions in Feminist Phenomenology
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From Armchair to Wheelchair: How Patients with a Locked-in Syndrome Integrate Bodily Changes in Experienced Identity

ABSTRACT

Different sort of people are interested in personal identity. Philosophers frequently ask what it takes to remain oneself. Caregivers imagine their patients' experience. But both philosophers and caregivers think from the armchair: they can only make assumptions about what it would be like to wake up with massive bodily changes. Patients with a locked-in syndrome (LIS) suffer a full body paralysis without cognitive impairment. They can tell us what it is like. Forty-four chronic LIS patients and 20 age-matched healthy medical professionals answered a 15-items questionnaire targeting: (A) global evaluation of identity, (B) body representation and (C) experienced meaning in life. In patients, self-reported identity was correlated with B and C. Patients differed with controls in C. These results suggest that the paralyzed body remains a strong component of patients' experienced identity, that patients can adjust to objectives changes perceived as meaningful and that caregivers fail in predicting patients' experience.